

Oregon's View of Legal Issues and Challenges in EPHT Implementation



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EPHT Implementation

- # National Network
- # Health and Environmental data
- # Systematic collection of surveillance and monitoring data
- # Geocoded and identified in some way that a user would be able to integrate and associate one with another

Health Data

- # Data collection for surveillance and research supports agency mandate to protect public's health
- # Data disclosure balances community's right to know with individual's right of privacy

Legal authority to mandate data collection

- # Mandatory reporting of certain conditions and conduct of special studies
 - ▣ Agencies usually authorized by State statutes and/or administrative rules
- # Data in state databases
 - ▣ Within agency, program
- # States will vary

..authority to mandate, con't.

Oregon reportable conditions

- Blood lead tests

- Cancer diagnoses - OSCaR

 - DHS statutory authority delegated to Health Services by admin rule

- Suspected pesticide poisonings

- Vital statistics

 - Statutory authority to use death records for public purpose

- No birth defects registry

Legal authority to access data collected by others

- # Health care, insurance providers

- # Federal law

 - HIPAA permits, but does not require, release of data to legally authorized PH agency for PH purposes

 - FERPA prohibits release of school record data without parental consent

- # State law may restrict further; Oregon not

..authority to access data collected by others, con't.

- # Permissive, not required
- # Data sharing agreements/Trading Partner Agreements
 - ▣ Legally binding/AG Office
 - ▣ Negotiated with data providers
 - ▣ Specifies which data, purpose, security, confidentiality
- # Terms and conditions will vary

Legal authority to disclose data

- # HIPAA silent

- # State - Public health data are confidential

 - Protected health information. ORS 433.008

 - Cancer Registry: All identifying information regarding individual patients, health care facilities and practitioners..shall be confidential and privileged. ORS 432.530

 - Public Records Law: The disclosure of such records is not required by the public records law...and is not permissible. ORS 164.512(a)

..authority to disclose data, con't

- # Does passing identified data to CDC's National Network constitute an impermissible "disclosure"?
 - ▣ CDC has authority to collect data
 - ▣ If Network exclusive to PH and CDC, researchers see summaries and IRB link, public sees summaries - maybe not?
 - ▣ Anything else, may well be

Environmental Data

- # Environmental agency usually authorized by statute to collect
 - Monitoring, data from regulated entities
- # Specific or general language
- # Publicly available
 - Except for protected business information/trade secrets
- # Often limited by resources, not law

Significance for Implementation

- # Unlikely to have identifiable data on National Network
 - ▣ No address - - implications?
- # Ability to have individual data on National Network may depend on
 - ▣ Agreements
 - ▣ Small numbers
- # Only aggregated?

Significance for Implementation

Implications for display

- Even if state has individual data to create an overlay map, may not be able to display data
 - Small #'s - identifiable

Important Q:

- What level of aggregation will satisfy confidentiality requirements and usefulness?

Significance for Implementation

* Legal parameters may drive:

▣ Network content

- ▣ Identifiable, individual, aggregated

▣ Network use, users

- ▣ PH agency, other agency, public

▣ Network structure

- ▣ State Networks separate from National?

Significance for Implementation

Legal support for Implementation

- Introduce Tracking legislation

- Expand reportability

 - Way to gather more health data

 - Statute or rule - What is agency empowered to do?

- Review of State PH laws - opportunity

Opportunity to share policy and legislative acumen

Significance for Implementation

Recommendation:

A uniform policy statement about the National Network that grantees can use with data partners

- ▣ HIPAA permissibility
- ▣ CDC authority to compile data
- ▣ Confidentiality restrictions
- ▣ Network data sharing, security